



## ECRD 2016 Edinburgh - Get Involved!



CNA - CEF, Paris, 28 October 2015

# CONTENT

1. EMM - ECRD 2016 Edinburgh: dates and venue
2. Official partners, overarching theme & conference themes, format
3. Website & New Features
4. How you can get involved

# 1. ECRD 2016 Edinburgh: dates and venue

26 – 28 May 2016





# Edinburgh International Conference Centre



**ECRD 2016**

**Over 850 participants**

## **2. Official partners, motto, overarching theme & conference themes, format**

**Organised by: EURORDIS**

**Co-organised by: DIA Europe**



# With the support of:



Co-funded by  
the Health Programme  
of the European Union



# AFMTELETHON

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# Official partners:



# ECRD Motto

- The European Conference on Rare Diseases & Orphan Products is the unique platform/forum across all rare diseases, across all European countries, bringing together all stakeholders - academics, health care professionals, industry, payers, regulators, policy makers and patients' representatives.
- It is a biennial event, providing the state-of-the-art of the rare disease environment, monitoring and benchmarking initiatives.

# ECRD Motto ctd.

- It covers research, development of new treatments, health care, social care, information, public health and support at European, national and regional levels.
- It is synergistic with national and regional conferences, enhancing efforts of all stakeholders. There is no competition with them, but efforts are complementary, fully respecting initiatives of all.

# Overarching Theme



## Game Changers in Rare Diseases

**Delivering 21<sup>st</sup> century healthcare to rare disease patients: Together we can change the future!**

# Conference Themes

Theme	Title
Theme 1	Game Changers in Research
Theme 2	Game Changers in Diagnosis
Theme 3	Game Changers in Drug Development, Authorisation & Access: Medicines & Adaptive Pathways
Theme 4	Game Changers in Care Provision
Theme 5	Game Changers in Social Policy
Theme 6	Game Changers in Global Society

# Format

Thursday 26 May: pre-conference day

- EURORDIS Membership Meeting (EMM) – General Assembly & Patient Advocates Capacity Building Sessions
- DIA Tutorials for industry and academia (open to patient advocates)
- Satellite Meetings eg. Orphanet, Helplines, etc.
- Patient groups welcome reception

# Format

## Friday 27 May: Day 1 of the conference

- Half day Opening & Plenary session
- Half day parallel theme sessions (6 themes)
- Dedicated poster sessions
- Speed networking session
- Networking reception



# Format

Saturday 28 May: Day 2 of the conference

- Parallel theme sessions (6 themes)
- Open house / « soap box » lunch session
- Dedicated poster sessions
- Closing Plenary session: take home messages

# 3. Website & New Features

# Website:

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26-28 May 2016 Edinburgh  
European Conference on Rare Diseases & Orphan Products

**GAME CHANGERS**

**ECRD 2016 : The European Conference on Rare Diseases & Orphan Products**  
26 to 28 May 2016  
Edinburgh

[Home](#) [Programme](#) [Posters](#) [Register](#) [Hotel & Travel](#) [Networking](#) [Exhibits & Support](#) [Infos & Downloads](#)

Search

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Programme

Day	16:00-18:00	18:30-20:00	19:00-20:30	21:00-22:30
Friday	Identifying unmet needs in rare diseases	ECRD 2016 Opening Ceremony	ECRD 2016 Gala Dinner	ECRD 2016 Closing Ceremony
Saturday	ECRD 2016 Day 2 Keynote	ECRD 2016 Day 2 Plenary	ECRD 2016 Day 2 Parallel Sessions	ECRD 2016 Day 2 Roundtable

Game Changers in Rare Diseases  
Delivering 21st century healthcare to rare disease patients: Together we can change the future!

## Bringing together all rare diseases, across all European nations

Following on from seven successful events, 2016 sees the 8th year of the ever-growing European Conference on Rare Diseases & Orphan Products. This biennial conference is a unique opportunity to come together and exchange: it is **the** event at which to connect and share with all other members of the rare disease community.

The ECRD is the only event which, from its small beginnings, has united all rare disease stakeholders from all European nations- patients and patient representatives, healthcare professionals and researchers, industry, payers, regulators and policy makers alike- in the fight against rare diseases. The ECRD now brings together over 80 speakers and more than 800 participants, covering six themes of content over two days: from the latest research, to developments in new treatments, to innovations in healthcare, social care and support at the European, national and regional levels. New meeting formats to enhance the on-site learning

**Website:**

**rare-diseases.eu**

**Other languages to follow in November:**

**French, German, Italian, Russian and Spanish**

# New features:

- In Partnership with Patients Theme
- Research speed-networking session
- Open house / « soap box » session

# 4. How you can get involved

# Patient Advocate Fellowships:

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**26-28 May 2016 Edinburgh**  
European Conference on Rare Diseases & Orphan Products

**GAME CHANGERS**

**ECRD 2016 : The European Conference on Rare Diseases & Orphan Products**  
26 to 28 May 2016  
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Programme Posters Register Hotel & Travel Networking Exhibits & Support Infos & Downloads

Schedule at a glance

Thursday, 26 May 2016

Friday, 27 May 2016

Saturday, 28 May 2016

Theme Descriptions

Pre-conference tutorials

**Patient Advocates Fellowship Programme**

Message from the Co-Chairs

Programme Committee

Organising Committee

Associate partners

are Diseases  
ry healthcare to rare  
ether we can

Search

Register >

Quick links

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Programme

eurordis.org

# Patient Advocate Fellowships:

The screenshot shows the EURORDIS website for the ECRD 2016 Patient Advocate Fellowship Programme. The header includes the EURORDIS logo, the event dates (26-28 May 2016 Edinburgh), and the 'GAME CHANGERS' logo. A navigation bar contains links for Programme, Posters, Register, Hotel & Travel, Networking, Exhibits & Support, and Infos & Downloads. The main content area features a sidebar with a table of contents and a main text area with details about the fellowship programme.

**ECRD 2016 : The European Conference on Rare Diseases & Orphan Products**  
26 to 28 May 2016  
Edinburgh

**GAME CHANGERS**

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Home Programme Posters Register Hotel & Travel Networking Exhibits & Support Infos & Downloads

> Schedule at a glance

> Thursday, 26 May 2016

> Friday, 27 May 2016

> Saturday, 28 May 2016

> Theme Descriptions

> Pre-conference tutorials

> EURORDIS Membership Meeting 2016

> **Patient Advocates Fellowship Programme**

> Message from the Co-Chairs

> Programme Committee

> Organising Committee

> Associate partners

## Patient Advocates Fellowship Programme

EURORDIS is offering patient fellowships for up to 40 patients' advocates to attend the 8th European Conference on Rare Diseases & Orphan Products (ECRD 2016) taking place 26-28 May 2016 in Edinburgh, UK.

These fellowships aim at empowering patients' advocates with networking opportunities, access to information and resources.

The programme covers:

- Registration (fee waivers or fee reimbursement)
- Travel (return trip economy fare flight or train)
- Accommodation (Up to 3 nights hotel accommodation in Edinburgh)

The total of the travel and hotel expenses reimbursed by EURORDIS cannot exceed 500 € per fellow.

Patient representatives wishing to benefit from this fellowship programme are invited to fill out and return the Patient Fellowship Programme Application Form here: <http://www.eurordis.org/sites/default/files/application-form-%20fellowship-ecrd-2016-edinburgh.pdf>

Deadline: 15 December 2015  
Submissions: [ania.helm@eurordis.org](mailto:ania.helm@eurordis.org)

**Deadline:  
15 December 2015**



# Call for Posters:

Contact us English

**26-28 May 2016 Edinburgh**  
European Conference on Rare Diseases & Orphan Products

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Programme Posters Register Hotel & Travel Networking Exhibits & Support Infos & Downloads

Posters

**Submit a Poster Abstract**

Poster submission for ECRD 2016 is now open

DIA are managing poster submissions, so please

Download the step by step guide to submitting your poster

**Deadline for Poster Abstract Submission: 31 January 2016**

Poster applicants will be informed of the decision by the Poster Committee by the end of February 2016.

**A conference organised by:**

**In partnership with:**

**Co-organised by:**

EURORDIS Rare Diseases Europe

orphanet Inserm

ORPHAN PRODUCTS DEVELOPMENT

healthier scotland SCOTTISH GOVERNMENT

NHS National Institute for Health Research

hope

Genetic Alliance UK Supporting, Empowering, Uniting.

EURORDIS Rare Diseases Europe

eurordis.org

# Other ways to get involved:

- Help us identify speakers/panelists for:

Session 0205:

Patients need accurate diagnosis

- We're looking for a patient representative « expert » (non-UK) who has experienced a diagnostic odyssey to ask questions to a panel of medical/clinical « experts »
- A video would also be good to include in this session: the difference a diagnosis can make to a patient's life

# Other ways to get involved:

- Help us identify speakers/panelists for:

Session 0302:

Patients as game changers leading us on the path

- We're looking for a short video (2 to 3 minutes) to open the session that illustrates the difference a patient's involvement in research can make in the development of new therapies/medicines for rare diseases

# Other ways to get involved:

- Help us identify speakers/panelists for:

Session 0401:

The Establishment of the ERN model for rare diseases

- We're looking for a patient representative to participate on the panel to articulate the expectations for ERNs from the patient perspective

Session 0402:

Patients navigating the healthcare pathways on a European and National level

- We're looking for two videos 1) providing a testimony from a family who has experienced working with a case manager, and 2) without a case manager

# Other ways to get involved:

- Help us identify speakers/panelists for:

Session 0405:

The opportunities and realities of ERNs in accessing healthcare in EU Member States

- We're looking for a video that portrays the positive experience of a patient having accessed quality healthcare due to either the expertise travelling or the patient travelling and what a difference it made to their life

# Other ways to get involved:

- Help us identify speakers/panelists for:

Session 0601:

The Impact of social media on globalisation: new knowledge generation and advocacy

- We're looking for 2 speakers to each give a 15-minute presentation in English on social media campaigns that have produced a high impact and made a difference for your rare disease community

# Other ways to get involved:

- Sign-up to participate in the research speed-networking session
- Share innovative strategies / approaches / services or projects during the open house / « soap box » session
- Disseminate promotional flyers at your meetings (available for patient advocates; researchers/healthcare professionals /academics; and industry)

**Thank you!**  
**See you there!**

